



## Parkinson patients as partners in care

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### SUMMARY

Increasing physical activity, as part of an active lifestyle, is an important health goal for individuals with Parkinson's disease (PD). Exercise can positively impact health related quality of life. Given this, how can we promote physically active lifestyles among PD patients (most of whom are sedentary)? Here we suggest that health care professionals could significantly expand their impact by collaborating with PD patients and their spouses (or caregivers) as *partners-in-care*. We outline reasons why partners-in-care approaches are important in PD, including the need to increase *social capital*, which deals with issues of trust and the value of social networks in linking members of a community. We then present results of a qualitative study involving partners-in-care exercise beliefs among 19 PD patients and spouses, and conclude with our perspective on future benefits of this approach.

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### 1. Introduction

Increasing physical activity (PA), as part of an active lifestyle, is an important health goal for individuals with Parkinson's disease (PD) [1,2]. Inactivity, which characterizes most PD patients, is prodromal, at least in animal models of PD [3]; higher intensity activity is thought to be protective [3,4]. Given this, how can we promote a long term, physically active lifestyle, among PD patients?

Current approaches to neurological rehabilitation involve highly trained multi-disciplinary teams. This assigns health care advisors and individuals with PD to two, non-overlapping groups: individuals with PD are “objects” or “subjects” of care, not “colleagues”, “collaborators” or “partners”. We believe allied health care professionals can significantly expand their health impact by inviting individuals with PD and their family members to become “partners-in-care” which, incidentally, breaks down some barriers between the medical community and patients [5]. We suggest that a partners-in-care approach can be clinically important in PD because it increases both PA and social capital of patients. We present results of a qualitative study assessing Parkinson patient and spouse beliefs about leading exercise using the partners-in-care model in which we interviewed participants with PD and spouses about the partners-in-care approach. We conclude with a future direction.

### 2. Patients as partners

Parkinson patients are the most underutilized resource in health care today (attributed to [5]). The proof-of-principle of involving patients with PD as partners in (exercise) care has been demonstrated (Fig. 1) [6]. In a randomized controlled trial led by the



**Fig. 1.** Two partners-in-care. Trainers with PD (Hoehn and Yahr stage I/II) from the first author's randomized controlled trial [6] (reproduced with permission; [7]).

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first author [6] the treatment (high intensity resistance and balance training) was administered by patients with PD and care-partners (spouses of patients with PD) and produced measurable changes in PD impairment, including improved postural control, and muscle strength, reduced falls on a standardized test of equilibrium, with no worsening in quality of life [6]. Here we present reasons why partners-in-care approaches (using PD patients and/or their spouses as health coaches), would be a logical “next step” in the evolution of neurorehabilitation, and would enhance the impact of health professionals while serving both PD patients and their spouses.

### 2.1. Shortage of rehabilitation professionals

Shortages of neurologists, PD nurse-specialists (RN) and physical therapists (PT), concurrent with increases in demand for their services, may reduce the quality of PD care [8–10]. Shortages in the number of neurologists, now at 11% in the United States, are expected to reach 19% within the next 10 years [8]. Similarly, shortages in skilled rehabilitation personnel, including RNs and PTs, are likely to increase both in the USA and internationally [11]. In the USA shortages in PT are expected to exceed 140,000 by 2030, particularly in skilled nursing facility settings, acute care hospitals and outpatient PT clinics [10]; these shortages will affect outpatient clinics where most of the PD rehabilitation now occurs [12]. Given projections, whom can individuals with PD turn to in order to continue to receive high quality care?

### 2.2. Increased number of patients

The number of PD patients will double by 2040, with concomitant increases in PD medical expenditures (currently \$12,800 per capita) and reduced PD patient employability [13]. Shortages in the supply of health care professionals, who have less time for patient encounters, and increases in the number of patients with PD will likely reduce the overall quality of PD care.

### 2.3. Care-partner health

Spouses serving as care partners of individuals with PD, who currently receive little or no training, display high levels of depression, anxiety and reduced health related quality of life; these factors become magnified with increasing disease burden [14]. Including care partners in the partners-in-care approach, and providing them with sufficient training, may have positive effects on both the PD patient and the care-giving spouse; we propose these benefits would include reduced mortality, reduced depression and anxiety, reduced care-partner burden and improved relationship satisfaction [15].

### 2.4. Social capital: Parkinson patients as health coaches

Since exercise has positive medicinal properties, while a sedentary lifestyle can enhance the degenerative process (at least in animal models), we need a big “evolutionary change” in how patients with PD participate in their treatment so that they take their “exercise medicine” on a regular basis. We think that our idea of promoting PD patients as health coaches will be a significant step in that direction. There is an additional, significant benefit to this innovation. To discuss this we introduce the concept of “social capital”.

Social capital relates to the value of networks in linking individuals within communities, and issues of trust [16]. In our case, the community consists of the multi-disciplinary collaborating health care teams, patients with PD, and their spouses and families seeking physical activity (PA). We suggest that increases in social capital will promote PA of this community. But how can we help PD patients build social capital?

Here we argue that a PD patient leading exercise in a social setting, such as a fitness center, can build new connections within

the community that support his or her efforts, and come to trust peers who exercise at this setting. This is likely to motivate living a more physically active life and promote positive health outcomes such as sustained increases in the amount of physical activity: a program to build such social capital needs to be developed.

## 3. Physical inactivity

It is becoming clear that exercise can become part of the treatment at all stages of PD. Unfortunately, up to 82% of individuals with PD demonstrate continuous low PA levels after diagnosis [17,18], and individuals with PD are 29% less physically active than healthy controls [19]. (Activity levels are lower for females than for males.)

Plausible activity reducing factors include problems with gait, advancing PD stage, anxiety, falls and fear-of-falling, impaired executive function, depression, and disability in daily activities or low outcome expectations [17–22]. However, in one study only 24% of the variability in PA was explained by various combinations of the above listed demographic and disease-related factors, leaving a large amount (~80%) of the variability unexplained [19].

In an attempt to increase PA and fitness, van Nimwegen and colleagues enrolled sedentary individuals with PD into a multi-modal behavioral change program (ParkFit) [21]. In this large scale, rigorous, double-blind study they randomly assigned PD patients (N=586) to two groups: (ParkSafe – physiotherapy aimed at moving safely and ParkFit – PT plus behavior change techniques, in which coaches used motivational strategies and ambulatory feedback to enhance the amount of PA). They used a standardized 7-day recall instrument over a long (24 month) follow-up period (loss to follow-up was low, 7.8%). Physical fitness parameters increased in ParkFit participants, with no significant change in the time spent on PA (ParkFit 7% increase; ParkSafe, 1% decrease,  $p=0.19$ ) or improvement in quality of life.

We suggest two reasons why there was no significant change in the proportion of sedentary PD patients in either group. First, trainers were all physical therapists working in a PT clinic so there was no opportunity for patients to acquire “lay role models”. Second, training was in a clinical setting and not in a public social setting, making it unlikely social capital increased. PD patients who exercise in public fitness centers report that, while they started exercising to improve balance, walking and muscle strength, they continued mainly because of exercise-related social support [23].

PD patients might become more active if they have a supportive home environment (e.g., spouses who favor exercise) and/or if exercising provides peer-support opportunities (e.g. PD support groups that convene at fitness facilities). There are currently no data to support this. We have now created a Parkinson alliance center in partnership with fitness centers in Mecklenburg County, North Carolina, which have begun to host PD patient support group meetings at select YMCAs (fitness centers) to boost adherence to physical activity. An evaluation of this concept is expected in 2015.

## 4. How do patients with PD envision their participation in health care?

Despite attention given to exercise and health promotion in PD over the last decades, what is appropriate and optimal care for patients and spouses of patients with PD is often filtered through the voices of the biomedical community “experts”. As a result we have learned little about how patients with PD envision shaping the future of health care.

### 4.1. Participants, data collection and analysis

We assessed PD patients’ beliefs about exercising with either their spouse or another PD patient. The study was approved by the institutional review board and a convenience sample of individuals with PD (confirmed diagnosis of PD according to established criteria,

**Table 1**  
Participant characteristics (n=20)

	PD patients (n = 11)	Spouses (n = 9)
Gender, male (%)	63%	37%
Age (yrs)	63.1±6.3	61.8±11.2
Race, white (%)	92%	100%
Years of education	16.9±0.9	15.8±1.3
MMSA	28.5±1.9	28.2±1.6
Employment status: Working, full or part-time (%)	45%	89%
Marital status: Married (%), duration (yrs)	81%, 35.1±10.5	–
Months since PD diagnosis at time of interview	26.6±36.9	–
PDQ-39 mobility dimension	10.2±15.3	–
CES-D	9.4±6.3	7.3±4.3
PT: never/previous year, or at present (%)	63%/36%	–
Ever talked to my neurologist about exercise – yes (%)	92%	–
Exercise amount (min/week), mean±SD (range)	202.7±260.3 (0–720)	90±112 (0–270)
Use of any assistive devices <sup>a</sup> (%)	8%	0%
PSI-PD <sup>b</sup>		
Difficulty with walking	10/1/0/0	–
Difficulty with transfers	6/4/1/0	–
Difficulty with balance	9/2/2/0	–
Problems with stiffness	5/5/1/0	–
Insufficient muscle strength (no/yes)	7/3 <sup>c</sup>	–
Felt tired quickly in the past month: (no/yes)	4/7	–
Number of falls in the previous year <sup>d</sup> : none/1/>1	8/2/1	–

Values are mean±SD, unless specified otherwise.

PT, physical therapy; PD, Parkinson's disease.

PDQ-39: Parkinson Disease Quality of Life Scale mobility domain score, range zero to 100 with higher scores indicating presence of more mobility disability.

CES-D: Center for Epidemiologic Studies Depression Scale, NIMH, range zero to 60, with higher scores indicating the presence of more symptomatology.

MMSA: Mini-Mental Status exam.

Exercise was defined as "a subcategory of physical activity that is planned, structured, repetitive, and purposive in the sense that the improvement or maintenance of one or more components of physical fitness is the objective" (see [24] pg. 250).

Exercise amount = self-report minutes of exercise in last 7 days.

<sup>a</sup> One participant with PD used a chair lift within their home.

<sup>b</sup> PSI-PD, Patient Specific Index in Parkinson's disease; no or slight (no help required)/yes/moderate (some help required)/severe

<sup>c</sup> 1 participant had missing data for this question.

<sup>d</sup> Self-reported number of falls in the previous year: none/one fall/more than one fall.

Hoehn and Yahr stage I and II), and care partners of patients with PD, who consented to participate, were enrolled through the outpatient Movement Disorders Clinic, Department of Neurology at Carolinas Medical Center. The patients with PD and spouses of patients with PD were interviewed in-depth and individually about their experiences with exercise and caregiving and, in this context, we asked two questions about patients with PD and spouses as health coaches: (Q1) "what do you think of the idea of people with PD as personal trainers of other people with PD?" and (Q2) "What do you think of the idea of a spouse of an individual with PD as a personal trainer of other people with PD?" The results were generated using qualitative research methods. The interviews were digitally recorded, transcribed to a written transcript and transcripts were coded, line by line, by MH. We reasoned that interviewees would generate data demonstrating: (a) "concerns" about whether or not people with PD or spouses should lead others with PD in exercise; (b) statements demonstrating "support" and (c) statements that were ambivalent. In-depth interviews with 11 patients with PD and 9 spouses of patients with PD provide data for the study.

In addition to the interviews, we assessed patient demographics and administered standardized instruments including the United Parkinson Disease Rating Scale – motor section III (UPDRS-III); cognitive status measure, the Mini-mental state exam (MMSE); depressive symptomatology measure, the Center for Epidemiologic Studies Depression Scale (CES-D); a quality of life measure, the PD questionnaire 39 (PDQ-39), patient-identified problem areas, the patient-specific index in Parkinson's disease (PSI-PD), and the Zarit burden interview (data not shown) [25–30].

#### 4.2. Results

Participants were 11 individuals with PD and 9 spouses of the PD participants. The PD patient and spouse participant characteristics are shown in Table 1. All PD participants were ambulatory without assistive devices, married, or living with an adult significant-other. Nine PD participants were taking carbidopa/levodopa. Most PD respondents reported infrequent or no impairment with walking, balance, or muscle strength. Rigidity (stiffness) was reported by ~50% of respondents. A single fall was reported by two participants and one other participant reported falling multiple times in the

**Table 2**Responses to questions about patients with PD and spouses as health coaches<sup>a</sup>

PD patient (PD)		Spouse (SP)	
ID	Response(s)	ID	Response(s)
1	Q1: "I think that would be fine because they can demonstrate the exercises and tell the other people what the advantages and what it's done for them." Q2: "Possibly, but I know it wouldn't be her first or second choice [chuckles]"	1	Did not participate
2	Q1: "I think that sounds pretty good ... I think they [the PD patients] would be taking it seriously". Q2: "My wife is an RN".	2	Q1: "Yeah! Why not? I mean all you need is a knowledgeable person" Q2: "Sure, yeah"
3	Q1: "Oh wow. I think it's great [starts crying]" Q2: "I think that would be an opportunity because they're right there. If you have somebody who's willing and interested to do that, yeah"	3	Q1: "I think that's a good idea ... her biggest high in life has been when, as a counselor, when she's been able to help someone" Q2: "I don't know if I would be good ... [pauses] I could see myself doing it. Yeah, I could see myself doing it and doing well at it".
4	Q1: "Not a bad idea ... you can help people with the same problem you've got. I think it would be good." Q2: "Well, if you don't get into an argument ... it depends on your relationship with your wife, your spouse. My wife and I have a really good relationship and she can help me"	4	Did not participate
5	Q1: "It would get me involved since I'm leading somebody else to help them ... It would put some importance to it." Q2: "sure, sure ... it would motivate me".	5	Q1: "I think that's great. I think that's fantastic" Q2: "I think that would be great because they (spouses) have lived with it and people can respect somebody who has lived with it."
6	Q1: "sure ... [laughing] in my spare time?" Q2: "I think that's a fabulous idea. I love that idea. If [my husband] were the person doing the training with me I would do it."	6	Q1: "I'm always a little – I'm in training myself – and I'm always a little skeptical because on paper it looks good ... Oftentimes if somebody is good at an exercise him- or herself, they are good at something. It doesn't translate into a good teacher. And sometimes that can be almost detrimental. So maybe a little bit ... but I would be reluctant to turn over too much responsibility to a peer trainer" Q2: "You're going to get some people who are natural. You're going to get others who, in my opinion, are going to make the person try too hard"
7	Q1: "I think it's a good idea. I think it's an excellent idea" Q2: "sure, I think she's a good teacher"	7	Questions not asked
8	Q1: "Oh that's an interesting thought ... seeing somebody that could do things or couldn't do things and that you don't feel as bad about what you can or can't do because somebody else is having difficulties too ... I wonder if it would make it less intimidating for someone to want to come [and exercise]? ... I'd have to think about it" Q2: "I don't know. I'm trying to picture, would he be too pushy. I think I like the idea of doing it together as opposed to him saying, 'No do it this way'."	8	Q1: "That's probably a good idea in that sometimes a physical therapist just doesn't know you can't quite do that and they want to take your arm and bend it all the way back or whatever, whereas someone who has Parkinson's says: 'I understand and I know you can't bend it and we'll work with you and see how far we can move it ... they may be more empathetic to that person as far as learning how to do the exercise." Q2: "I don't know, it's hard to say."
9	Q1: "Sure, I mean ... I don't have a problem with that." Q2: "Personally, I think my husband would really get into that because that's what he always wishes he had done with his life ... there may be too much of a comfort level for me to say things to him that I wouldn't say to somebody I don't know that well ... I think he would get frustrated or tend to let me slide"	9	Q1: "I think it's great. I think that would be great" Q2: "Well, I don't know. Sometimes a personal trainer can get a little too close. So I don't know ... I go back to I quit coaching my son's teams a while back for a reason and it's because I'm dad to him and he really doesn't listen to me the way he listens to another person in that role".
10	Q1: "I think that would probably be a good idea providing the person had to be certified or licensed or controlled ... there are too many people out there right now who call themselves personal trainers and basically they're body builders." Q2: "Yeah, I think that would probably be a good idea. I think it would probably be a very good idea for the person with Parkinson's disease, properly trained"	10	Q1: "That might be a good thing because if they can show what they can do to somebody who needs to do it, I think that would be a big plus." Q2: "That, I don't know that will work, not for my husband anyway because my husband won't listen to me ... somebody else, that might work"
11	Q1: "I think it would be stressful [for me] ... I would stress about it quite a bit – mental stress – and the fact that I have to be someplace and have to be prepared ... but I might consider it." Q2: Question not asked	11	Q1: "He would be superior." Q2: "Oh I would love to be coached in doing any of that. I just find it fascinating".

<sup>a</sup> **Question 1 (Q1):** What do you think of the idea of people with PD as personal trainers of other people with PD?**Question 2 (Q2):** What do you think of the idea of a spouse of an individual with PD as a personal trainer of other people with PD?

Two spouses declined to participate. In two interviews (#PD11, SP#7) questions were not asked due to interview error.

last year. In 63% of the PD participants, an exercise program had been developed by the respondent or spouse. Less than 50% of the PD respondents had ever been to a physiotherapist. Half of the PD respondents believed "an exercise instructor in a fitness center would not know how to set up an exercise program for me". The

predominant belief among PD patients was that "exercise will not worsen my condition", but 54% reported "my doctor never told me to do any specific exercise". Table 2 shows the PD-participant (PD) and PD-spouse (SP) participant statements made in response to the two exercise interview questions. Analysis of the statements

revealed three themes (“concern”, “support”/“lack of support” and “ambivalence”).

#### 4.2.1. Can people with PD serve as trainers?

Fifteen statements (8 by PD, 7 by SP) were coded as “supportive”, including: “PD 10: I think it’s a good idea”, “PD 2: they would be taking it seriously”, “SP 3: her biggest high in life has been when, as a counselor when she’s been able to help someone”, “SP 8: sometimes a physical therapist just doesn’t know you can’t do that” and “PD 8: I wonder if it would make it less intimidating for someone to come”. Four statements (PD, 2; SP, 2) were “unsupportive” or demonstrated “concern” including: “PD 6: sure ... [laughing] in my spare time?”, “PD 11: it would be stressful – I would stress about it quite a bit”, and “SP 6: reluctance to turn over too much responsibility to a peer trainer” and “SP 6: oftentimes if somebody is good at an exercise themselves ... it doesn’t translate into a good teacher”.

#### 4.2.2. Can spouses of PD patients serve as trainers?

Seven responses were “supportive”. Examples include: “PD 5: sure, it would motivate me”, “PD 3: I think that would be an opportunity because they’re right there”, “SP 11: I would love to be doing that”; 8 respondents were “unsupportive” or expressed “concerns”, including: “PD 1: I know it wouldn’t be her first choice”, “PD 4: it depends on your relationship”, “PD 8: he would be too pushy”, “SP 6: You’re going to get some people who ... are going to make the person try too hard”, and “SP 10: my husband won’t listen to me” and 1 was coded “ambivalent”: “my wife is a registered nurse”.

## 5. Conclusions and future direction

The number of PD patients is increasing while the number of neurologists and allied health care professionals is decreasing: without a remedy unmet needs will increase. Reducing the percentage of PD patients who are sedentary would be “strong medicine” and could reduce the burden that health care professionals carry. We think preparing PD patients and their spouses as health coaches can play a significant role in meeting needs of persons with PD (and improving the quality of their lives). Few recognize the forceful and positive impact that patients and their spouses (or caregivers) working collaboratively with health professionals can have on the current health care system [5].

Parkinson’s disease is a highly debilitating condition requiring care for a lifetime. Maintaining (and increasing) the quality of health care for patients with PD through patient-participatory approaches will require a transformative shift in our thinking about what patients are capable of.

Our suggestion of involving PD patients and care-partners as health coaches raises justifiable questions and concerns. First, there are risks of this approach, including the potential for increasing caregiver burden; this would be counterproductive. Furthermore, poorly trained PD patients and/or their spouses could generate added stress in PD patients; this would also add to the burdens of both PD patients and their caregivers. As with all medical advances, there is a need for safety and effectiveness studies. Second, there is no empirical evidence that PD-specific knowledge of exercise and ability can be improved in lay individuals, and if it can, whether this will promote a better health outcome with cost-containment.

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## Conflict of interests

The authors have no conflicts of interest to declare.

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